

Written testimony of Jennifer Seiderer of Weatogue in Support of

**HB 6975 AN ACT ESTABLISHING A TASK FORCE TO STUDY LIFE-THREATENING  
FOOD ALLERGIES IN SCHOOLS**

Education Committee Public Hearing

Wednesday, March 11, 2015

Room 2C

Chairman Fleischman, Chairman Slossberg, Members of the Education Committee, for the record my name is Jennifer Seiderer and I am writing in support of **HB 6975 AN ACT ESTABLISHING A TASK FORCE TO STUDY LIFE-THREATENING FOOD ALLERGIES IN SCHOOLS**.

I am writing today on behalf of my six-year-old son, Eli, who started kindergarten this past August. Eli has a life-threatening allergy to peanuts. At the age of thirteen months, Eli experienced anaphylaxis when I gave him a bite of peanut butter. For those of you who don't know what anaphylaxis is, I wish I didn't know. After just one bite of peanut butter, Eli's lips swelled grotesquely and he began to wheeze as his throat began to close.

Since that day, my husband and I have done everything we could to keep Eli safe. To get ready for Eli to start school, we researched local, state and federal food allergy guidelines; we gathered sample Individual Health Care Plans; we spoke to pediatricians and allergists; we attended trainings on Section 504 of the 1973 Rehabilitation Act and we spoke to many food allergy advocates, experts, and other parents who were in the trenches. We made sure that we knew what to ask for and how best to partner with our son's soon-to-be school to make Eli as successful as possible. We started a dialogue with the school a full six months before his first day of kindergarten as we anticipated that there would be many issues to resolve. We had no idea how long it would take.

Over the course of those six months, we spoke with numerous representatives from the school and had several in-person meetings. We also provided them with educational materials on how to handle food allergies in the school setting.

While the school was happy to receive our materials and they always treated us courteously, my husband and I were surprised at the lack of existing guidelines and protocols when it came to food allergies. Though they already had a nut-free cafeteria table (at which no one sat, they informed us), they seemed unfamiliar with the concepts of reading labels, hand washing to remove allergens, or other of the more common safeguards. On two different occasions, school

staff tried to dissuade us from obtaining a Section 504 plan for Eli, which is his right and their responsibility to offer.

Despite the continued dialogue, Eli's Section 504 plan was not finalized and signed until two days before school started. Safe transportation for Eli to and from school was not finalized until the day before his first day of kindergarten.

While Eli's father and I have fought hard for Eli's rights in school and have mostly succeeded in shielding our six-year-old from the stress of having to deal with his food allergy, kids pick up on everything. Eli has asked why he could not eat the popsicles that the principal provided for the entire school. He has exited the school bus in tears after being asked by the bus driver to leave because she couldn't take him without his school-provided paraprofessional there to keep him safe. Eight months in, there have been many small 504 violations that we have not fought over because we didn't have the energy and wanted to pick our battles in order to make Eli feel as normal and included as possible. We also didn't want to strain our relationship with the school staff.

My husband and I consider ourselves very well-informed about food allergies but even so, the school process should not be this hard. We should not have to fight tooth and nail for every accommodation, accommodations that are needed to keep our child safe and included.

In addition to representing my own son as I write today, I'm also writing on behalf of the No Nuts Moms Group of Simsbury, an online support group of over ninety local families of children with life-threatening food allergies. Although my husband and I have been largely successful in advocating for Eli at school, other Connecticut parents of kids with life-threatening food allergies have not been so lucky. I think you may hear from some of those other parents in person or in writing, but I hear time and time again of other parents having to battle their schools, Boards of Education, and even other parents to have their children's needs met. Protocols across the state are non-existent or inconsistently enforced if they do exist. Every single parent is having to reinvent the wheel when it comes to handling food allergies in the school setting and this has got to change. Not all parents have the resources to advocate for their own children the way that my husband and I have. More disadvantaged kids shouldn't be denied the same accommodations and inclusion.

That's why we're asking you today to support HB 6975. Despite ongoing research and encouraging medical breakthroughs, the problem of food allergies is not going away any time soon. This potentially deadly disease affects one in every thirteen children under the age of eighteen.

It's time to create – and enforce – standard protocols across the state so that every child with life-threatening food allergies has the same access to public education. It's time to standardize policies not just about the safety of these kids but also about their inclusion and emotional well-being. It's time to make sure that state guidelines that do exist are being applied and that there are clear parameters for the implementation of these guidelines at the local level. I'm hopeful that this new task force can do exactly that.

Because I nearly lost my son five years ago to one bite of a peanut butter sandwich, I fought like a grizzly mama to keep him safe and get him what he needs. Parents of kids with life-threatening food allergies should not have to fight this same battle over and over again, alone. In this bill, I'd respectfully ask that you reconsider having only one parent on the task force. There are many different stories across the state and a wealth of information and experience that we can share. I'd hate to have us underrepresented as partners at the table.

It's worth noting here that my husband and I were also working directly with Representative John Hampton on HB 6272 AN ACT CONCERNING THE ADMINISTRATION OF EPINEPHRINE ON SCHOOL BUSES. It's our understanding that that effort may be rolled into this task force for consideration. We feel strongly about that issue as well and are hopeful that it will become part of this task force's mandate as it is so closely aligned. To that end, I've included below our written testimony on that bill and a link to the interview that we did along with Representative Hampton.

Thank you for the opportunity to submit my testimony and thank you in advance for your support of this bill.

Jennifer Seiderer  
Parent  
Leader of No Nuts Moms Group of Simsbury

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Written testimony of Gregg and Jennifer Seiderer of Weatogue in Support of

**HB 6272 AN ACT CONCERNING THE ADMINISTRATION OF EPINEPHRINE ON  
SCHOOL BUSES**

February 22, 2015

Dear Representative Hampton,

Thank you for the opportunity to share our story and hear our concerns about the lack of administration of epinephrine by trained adults on school buses, proposed H.B. No. 6272.

Our son, Eli, has a life-threatening allergy to peanuts. He has experienced anaphylaxis -- lips swelling, wheezing, throat closing -- with one bite of peanut butter. He started kindergarten at Central Elementary in Simsbury on August 27, 2014. We initiated conversations with the school about Eli's peanut allergy in February of 2014, a full six months before he was to start school.

The one issue that was not resolved until August 25<sup>th</sup>, two days before school started, was transportation to and from school.

When we first met with the school in April, we were told by the Simsbury Director of Health Services that she personally conducts yearly training for bus drivers on the signs and symptoms of anaphylaxis. When we asked if this meant that the bus drivers would actually administer the epinephrine, we were told that they would not. Their emergency protocol instructs them to pull over to the side of the road and call the Salter's Express Company dispatch, who would call 911. When we indicated that this was not acceptable because anaphylaxis can kill a child in minutes, we were told by the Director of Health Services that "educational law" prohibits bus drivers from administering epi. We asked for a citation for this law; we never received any such citation.

The Director of Health Services then recommended that we contact the Transportation Coordinator to see if Eli could be picked up last and dropped off first, thus minimizing the amount of time he would be at risk.

When we contacted the Transportation Coordinator via phone, we were told that they would not pick up Eli last and drop him off first because "that does not make sense." The Coordinator was unwilling to even discuss it. She indicated that based on where we live, Eli would be on the bus for a half hour each way and if he is "that allergic," he should be able to self-administer the epinephrine. We pointed out that not only is he only five years old, but anaphylaxis often impairs breathing and causes a drop in blood pressure and loss of consciousness, so we would be reluctant to have even a much older child self-administer, let alone a kindergartener. We also said that this is not approved by his allergist.

The Transportation Coordinator told us that bus drivers are not allowed to administer epi per the Director of Health Services, who tells them that every year. The Coordinator said she doesn't know why they are prohibited, whether it's because of medical liability or some other reason.

When we asked how children in wheelchairs or with other special needs are accommodated, the Coordinator said that they are handled by Special Services and have a PPT plan. We asked what this was and she said it is a Planning and Placement Team. Once that plan is in place, she is notified to remove the child from her transportation list because Special Services takes care of the transportation.

We then contacted the Director of Health Services again to tell her that things had not been resolved with the Transportation Coordinator and that, under the Section 504 plan for Eli's disability, it is the school's legal obligation to ensure safe transportation for Eli.

On August 22<sup>nd</sup>, five days before the start of school, we met with the school again to finalize and sign off on Eli's Section 504 plan. At that meeting, nothing had been resolved about transportation, though the Director of Health Services and the newly hired principal both said that they knew it was their responsibility. They indicated that if they had to, they would hire an epi-trained paraprofessional to ride the bus with Eli.

On August 24<sup>th</sup>, the principal called to inform us that they had, in fact, hired a paraprofessional to ride the bus with Eli. We thanked her and indicated that once that was added to his Section 504 plan, we would sign off on it.

Later in the day on August 24<sup>th</sup>, we received four voicemails from the Special Services Supervisor, asking us to call her about transportation. We contacted the principal instead, who told us that Salter's Express Company would not allow the paraprofessional to park her car at Salter's lot in order to get on the bus at the beginning of the route. The school had then arranged with a neighbor of ours to allow the paraprofessional to park at their house, but Salter's would not pick up the paraprofessional at a stop with no children getting on. The principal then asked if the paraprofessional could leave her car at our house every day and get on the bus with Eli but we said no as this singles him out and makes him a target for bullying. She said she would get back to us.

From the final 504, which was not signed until 8/25, the day of kindergarten orientation: "All bus drivers will be in-serviced annually on the signs and symptoms of anaphylaxis including implementing Simsbury's emergency response procedure. The existing policy of no eating or drinking on the bus will be strictly enforced. Eli will be sitting in the first few seats that are designated for Kindergarten students. Eli will have an EpiPen trained employee available for transportation to and from school. Parents will be available for transportation on an emergency basis."

On August 26<sup>th</sup>, the day before school started, the principal called and told us that the transportation had been worked out. The paraprofessional would park her car at Simsbury High School and walk to Salter's lot (approximately two blocks away) to board the bus at the beginning of the route. She would get off the bus with the students at Central and reverse the route in the afternoons, returning to Salter's and walking back to her car at the high school.

Since the beginning of the school year, there have been three occasions when the paraprofessional was not available. On the first occasion, we were not notified ahead of time and Eli actually boarded the bus. The bus driver waived down Jennifer and demanded that she remove Eli from the bus, saying that she "couldn't take him." Eli was upset and crying, and Jennifer had to drive him to school. On two other occasions, the school called right before the time of pickup, asking Jennifer to drive Eli to school. On numerous other occasions, Jennifer noticed the Central School Nurse riding the bus to accompany Eli instead of the paraprofessional. The principal confirmed that the school nurse is the backup for the paraprofessional.

We are extremely grateful to you for proposing this bill and want to assist you in any way we can. We're a little concerned that the wording of this bill as proposed will allow the bus drivers a loophole, though.

“To ensure that there is a trained adult on each school bus that is qualified to administer epinephrine in the case of an emergency, reduce response times in such circumstances and save lives.”

Our concern is that the bus drivers may be trained to administer epi but may be instructed not to do so for liability or other reasons. The emergency protocols would need to be updated as well. In the case of Salter’s, instead of pulling over and calling Salter’s dispatch, who then calls 911, the protocol should be to pull over, administer epi, and then call 911 themselves, while watching to see if another epi is required before assistance arrives.

In addition, the proposed bill as worded would not require Salter’s Express Company, or any other transportation provider, to do anything differently. Our current legal agreement with the school to provide a paraprofessional for Eli would satisfy the bill. Why would Salter’s not put this responsibility back on the school as they have done thus far?

Even if this bill is not passed in time to help our child, this potentially deadly disease affects 1 in every 13 children under the age of eighteen. Death from anaphylaxis can occur in minutes.

Thank you for your consideration.

Sincerely,

Gregg and Jennifer Seiderer  
Parents  
Leader of No Nuts Moms Group of Simsbury (Jennifer)

Link to interview with Mr. and Mrs. Seiderer and Rep. Hampton on WSFB:  
<http://www.wfsb.com/video?autoStart=true&topVideoCatNo=default&clipId=11175673>